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The Digital Transformation of Patient-Reported Outcomes' (PROs) Functionality Within Healthcare

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Abstract. This paper elucidates how the functionality of Patient-Reported Outcome (PRO) has evolved due to its digital transformation. Hence, PROs traditional use within healthcare is described and compared to the application of electronic PROs (ePROs); leading to a discussion regarding PROs functionality. The literature included in this paper stems from a systematic scoping review. The digitalization supplements former functionalities of PRO by enabling timely, accessible, systematical and progression oriented data; however, further improvements are necessary to enhance PROs application in current healthcare.

Keywords. Patient-reported outcome, PRO, digital mediation, ePRO and PROs functionality

1. Introduction

Patient-reported outcomes (PROs) are increasingly used in current healthcare due to their multidimensional functionality, among other things, made possible by the digitalization of PRO. An alteration in the use and mediation of PROs, which have shown to be feasible [2], also as part of clinical practice [1].

A commonly used definition of PRO was coined by the American Food and Drug Administration (FDA) in 2009, stating that PRO is: "Any report of the status of patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else" [3].

Traditionally, PRO-questionnaires was used to test the effect of new drugs on patients, and as aggregated data targeted research purposes [5]. However, more extensive use of PRO in clinical practice is currently gaining ground within healthcare. Thus, data is no longer preserved clinicians and scientist, since PRO-data now is expected to inform, include and actively engage patients in managing their own disease [6]. Therefore, PROs integration into clinical practice has altered its current purpose and functionality [7].

Hence, this paper provides an overview of PROs functionality pre and post its digitalization and discuss ongoing challenges.

2. Method

The literature included in this article stems from a systematic scoping review regarding the link between PRO and patient participation. A comprehensive review,

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which therefore also provides an overview of PROs functionalities and digital transformation. Hence, the articles in this paper are a selective extraction, included if they pertain to PROs functionality pre or post its digital mediation.

The publications were identified using the following databases: PubMed, Embase, CINAHL and Scopus. The objective was to identify associations between patient participation and PRO. When conducting the search, the word 'patient-reported outcome' was included every time, and then combined with search words covering either: 'patient recognition', 'patient participation' or 'patient empowerment'. Exclusion criteria pertained to studies regarding primary care, traditional research studies where PRO was used as a secondary endpoint and studies where children were the subject field. Inclusion criteria consisted of articles covering, e.g. PROs used at hospitals or outpatient clinics, articles examining PROs effects, directly as well as indirectly. This strategy resulted in 6.895 articles; decreasing to 4.343 after duplicates had been removed. After reading and sorting the abstracts 256 articles were fully read and assessed for eligibility [8]; hereof, 27 articles are included in this article.

3. Applications of PRO

3.1. PROs functionality

Originally, PRO was used for group-level research and medical research, as supplement data/secondary outcome measures in clinical trials, e.g. in randomized controlled trials (RCT) studies, testing new drugs and evaluating the comparative effectiveness of healthcare interventions. Thus, the collection of PRO-data established a systematic approach when eliciting patients perspective on what mattered to them regarding their health status, their experiences pertaining to adverse effects, side-effects, comorbidity, and the burden of illness or treatment [5][9].

Therefore, the integration of PRO means that the evaluation of treatment no longer merely is based on objective criteria and physicians assessments, but on patients' perceptions and experiences as well [4]. A shift of focus in healthcare interventions, emphasizing the importance of patients health-related quality of life (HRQoL) to complement more traditional survival measures [10].

3.2. ePROs functionality

Furthermore, the digital transformation of PRO may enable new functionalities.

Firstly, when PRO is digitally mediated it allows real-time monitoring of patients and timely-data becomes available during patient-clinician consultations; potentially, leading to tailored patient management, improved decision making, more accurate diagnosing and better treatment [11].

Secondly, accessibility of PRO-data changes when digitalized as it enables patients to access data from at home; allowing them to follow their disease progression systematically over time. Therefore, the completion of ePRO-questionnaires potentially initiates a learning process as patients are confronted with issues pertaining to their condition; thus, PRO-data might empower and engage patients [12]. This feature, coupled with patients opportunity to track their disease progression over time and, e.g. set disease-related goals, are focal reasons why PRO-data is perceived as a self-management tool [13]. Thus, ePROs increased accessibility potentially improves patient

participation and self-monitoring as part of patients everyday life [13][14]. Moreover, ePROs might also affect patients' ability to engage more actively in conversations with healthcare professionals; potentially, enhancing shared-decision making in clinical practice [11].

Furthermore, improved accessibility also means that PRO can be used as a coordination tool as it supports organizational information flows on both a vertical and horizontal level. In other words, the digitalization of PRO potentially enables healthcare teams and providers on different organizational levels to share data. As a result, stakeholders are able to base decisions on timely data, while patients' avoid having to complete similar questionnaires over and over again, as they progress through the healthcare system [7]. However, this feature of PRO-data arguably relies heavily on adequate digital infrastructures [15] and regulations like, e.g. GDPR.

Thirdly, the systematic digital collection of PRO-data offers stakeholders an opportunity to plan and execute healthcare based on population data; exemplified by the value-based healthcare (VBHC) approach, where the reduction of health care costs and efficient use of resources are central aspects [16]. Thus, VBHC, via the use of digital PRO-data, might enable benchmarking, reimbursement and accountability of healthcare providers based on values pertaining to patient preferences and economic efficiency [14]. Moreover, this application of PRO-data might be used to improve systematic knowledge sharing among healthcare providers [14].

Lastly, PRO, as part of a triage system, is an example of a more recent application. The system is based on algorithms, which sorts patients into different categories (green, yellow and red) according to their health status; subsequently, determining who needs to show up for a patient-clinician consultation. Hence, some patients are able to skip unnecessary routine consultations, which ensures that those patients who are in need of medical attention, are prioritized [17].

Table 1. PROs functionality on an individual and population level pre and post its digitalization.

Stakeholders[2]	Functionality	Pre digitalization (PRO)	Post digitalization (ePRO)
C	Decision-making and treatment [11]	x	x
C	Diagnosing [18]	x	x
CP	Patient perspective [4][6]	x	x
CP	Shared-decision making (SDM) [6]	x	x
CI	Drug testing [19]	x	x
CI	Research [14]	x	x
CPM	Patient-centred healthcare [14][20]	x	x
CP	Communication/dialogue [13][20]	x	x
C	Screening [11][20]	x	x
CPM	Patient satisfaction [6]	x	x
P	Patient participation [6]		x
P	Self-management [6][13][14][17]		x
M	Health policy development [21]		x
CPM	Quality of care [1][14][20]		x
CM	Best practice [14]		x
CP	Adherence [6][15]		x
M	Reduce health care costs/efficient use of resources [22]		x
CM	Triage system based on algorithms [17]		x

[2] Stakeholder terminology: C – clinicians, P – patients, M – managers/politicians, I -industry

P	Patients goals [15]	x
M	Monitor population health/preventive tool [7]	x
C	Monitoring and patient management [22]	x
M	Value-based healthcare (VBHC)/ Benchmarking/Reimbursement/ Accountability [16]	x
CM	Coordination tool/ Interdisciplinary/multidisciplinary communication [20]	x
P	Patient Empowerment [23]	x
P	Self-monitoring [24]	x

Table 1. Demonstrates how the digitalization of PROs has altered its functionality. Thus, PRO has changed from mainly being a tool used by clinicians and industry for research and drug testing, to now also being a tool used by patients, healthcare managers and politicians, e.g. facilitating systematic patient participation, patient management and VBHC.

4. Discussion

The paper elucidates how the digitalization of PROs has changed their functionality and purpose. However, even though the digitalization has improved and innovated PROs functionality, certain issues pertaining to the application and implementation of PROs still persist.

Therefore, even when ePROs, in some cases, might increase data accessibility, the use of PROs in healthcare can also exclude particular groups of patients. Thus, low health/eHealth literacy [25][26] and lack of technological access [19][22][27], are factors which potentially exclude patients; subsequently, creating a barrier towards patient participation. Hence, clinicians and managers need to be aware of the patient burden PROs might entail [22][27], to make sure that the use of PROs enables patient empowerment and not turns into patient work [28].

Furthermore, it is essential to make sure that PRO-data is actionable [6] and actually used in clinical practice since this is not always the case [29]. Therefore, to secure the use of PRO-data in clinical practice PRO measures need to be clinically relevant [22][29], and clinicians should be trained regarding the application and interpretation of PRO-data [29][30]. Whereas, on an organizational level, attention to how workflows are affected [27] and whether sufficient time is allocated for meaningful use of PROs [30] is needed.

Hence, even after PROs digital transformation, there is still a lot of work to be done to make sure that PRO fulfil its potential, which is why further research within this area is recommended. However, as the overview in table 1. Demonstrates, ePROs have the potential to further a more personalized and actively engaging approach in healthcare.

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